

Written Testimony of Steven Kroll Executive Director, NYSARC, Inc.

Submitted to the Joint Fiscal Committee for the 2015-16 Budget

February 27, 2015



393 Delaware Avenue, Delmar, NY 12054

Tel: (518) 439-8311 | Fax: (518) 439-1893 | www.nysarc.org

Executive Summary of Written Testimony of Steven Kroll Executive Director, NYSARC, Inc.

Submitted to the Joint Fiscal Committee for the FY 2015-16 Budget

I am Steven Kroll, Executive Director of NYSARC, Inc. NYSARC is the nation's largest parent governed nonprofit organization serving people with developmental disabilities. On behalf of NYSARC, I want to thank the Fiscal Committees for this opportunity to present the issues and priorities of NYSARC concerning the Governor's proposed FY 2015-16 budget request for services to people with developmental disabilities.

This budget request comes at an important point in time. The entire service system is in the process of adjusting to a rapidly changing environment. That environment includes such items as the increasing needs of people who live at home and are cared for by aging caregivers; reforms required by the Transformational Agenda; the need to provide competitive and integrated employment to people with developmental disabilities; the prospects for managed care to transform services; and, many other important issues which are covered in my written testimony.

I want to laud the Governor's budget proposal for including some very critical funding initiatives. Those include full funding for the two year Cost of Living Increase enacted by the Legislature last year. The proposal includes funding for development of important new service opportunities. It does not cut services and it reserves state funds to meet potential repayment obligations to the federal government, without putting the OPWDD service system at risk. From our perspective, there are three key issues that we would highlight for your consideration:

- First, NYSARC has launched an advocacy campaign entitled "Families Cannot Be Caregivers Forever." This campaign recognizes the increasing needs of families, often elderly parents, who can no longer provide safe and appropriate care for their adult children with developmental disabilities. Many of these parents have significant age related disabilities. Their numbers appear to be increasing. It is our hope to work with the Legislature and the Governor to make important strides forward in resolving this important issue.
- Second, the system of preschool special education is undergoing enormous strain. Preschool programs are reimbursed significantly below cost. They haven't seen a rate increase in 6 years. These programs have proven their ability to reach children at an early age and reduce the severity and cost of dealing with disabilities later in life. It is important to work with both the Legislature and the Governor to protect these programs for the children they serve now and for those children who will need these programs in the future.

- And, finally, there is an urgent need to provide people with developmental disabilities much greater access to employment as part of the Governor's Employment First Initiative. NYSARC strongly supports this goal. It is part of the Governor's Transformational Agenda agreed to with the federal government. We are pleased that the Governor's budget recognizes the need for additional resources to accomplish these. However, we believe that further help is needed.

These and others are the issues now before us. Again, I look forward to working with the Legislature and the Governor to make important strides forward during this budget session.

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Members of the Committees:

On behalf of NYSARC, Inc., I want to thank you for opportunity to testify today. I am Steven Kroll, the Executive Director of NYSARC.

NYSARC is the largest family governed nonprofit agency supporting people with developmental disabilities in the nation. NYSARC supports over 60,000 people with developmental disabilities and their families through 48 Chapters operating in every region of the State. NYSARC has been a proponent of supporting people with intellectual and developmental disabilities in the most integrated setting appropriate to their needs since our inception 65 years ago. Every local NYSARC Chapter provides an array of day and residential services, supports and programs that impact virtually every aspect of life.

CORE MISSION AND FAMILY ORIGIN

Since our founding in 1949, NYSARC's mission has been to include people with developmental disabilities as full citizens of their communities. The parents who began NYSARC joined other family members like them throughout the country to advocate for laws and court decisions forming a legal basis for an inclusive society. In one way or the other, family members from all walks of life were critical to the advocacy which resulted in a legal framework for change. Decades of legislative and legal battles and triumphs paved the way for moving people with developmental disabilities from substandard conditions in segregated institutions to an inclusive life of dignity and respect among their families, peers and friends in local communities.

While these historic developments established a vision for change, the State budget determines whether that vision remains a reality.

THE STATE BUDGET AND EVOLUTION OF SERVICES

From the Institution to the Community – From the time of the historic Willowbrook Consent Decree (1975) to the present, the State budget has been the vehicle for moving from an institutional system to a community based system of care. The population of New York's state institutions for people with developmental disabilities (developmental centers) went from nearly 27,000 individuals in 1967 to less than a few hundred today. Developmental centers have been replaced by community based services which now include nearly 40,000 community-based residential placements and nearly 100,000 non-residential placements including day habilitation, supported work, family support services, and community habilitation, many of which are overseen and operated by our Chapters.

The Transformational Agenda – Over the past 3 years this vast and complex disability service system has entered another era of profound change. The State’s Transformational Agenda has been designed to provide more choice, align services to the needs of the individual and facilitate greater community integration. The Transformational Agenda is intended to fully implement the Americans with Disabilities Act and the U.S. Supreme Court’s Olmstead Decision.

Transformational goals include more integrated and competitive employment for people with developmental disabilities; smaller and more intimate residential settings; complete deinstitutionalization; and moving to a managed care system of reimbursement.

The Reality of Transformation: Anxiety and Concern – NYSARC supports the intent and goals of the Transformational Agenda. By the very nature of their life long journey and the history of our organization, the families of NYSARC are reformers. It is part of our DNA. But, families also see a Transformational Agenda that is fraught with uncertainty. Longstanding programs are being phased out, without clarity as to what will replace them. The uncertainty surrounding managed care and other elements of the Transformational Agenda has led many of our families to experience profound anxiety and deep concern over what the future holds for their loved ones.

NYSARC also recognizes that the Transformational Agenda will likely cost more, not less, to implement. For example, staffing needs, the largest component of cost, will increase, rather than decrease, as settings become smaller. Despite the need for more resources, since 2011 the State has achieved savings from the developmental disabilities system estimated at \$209 million per year.

Additionally, while the field is being directed towards managed care, there is deep concern about its impact on people with developmental disabilities and little clarity about anticipated savings or the adequacy of rates that are still under development. NYSARC supports Acting Commissioner Delaney’s decision to pause the implementation of managed care and is pleased to be participating in the “Transformation Panel” convened by the Acting Commissioner.

THE STATE FISCAL YEAR 2015-16 BUDGET

We should note, at the outset, our sincere appreciation for and strong support for the Governor’s commitment to funding the cost of living increase for direct support professionals that the Legislature mandated last year and for the substantial increases in funding for expanded residential and community-based services I describe below. We are also grateful that he has set aside funds in this budget to address the potential State repayment of Medicaid funds to CMS that may be required and that might otherwise result in an unfair and unsustainable cut to programs in this field.

Beyond the dollars and cents, with so much happening simultaneously, NYSARC’s families are desperate for clarity. We believe that additional detail in this budget would help give advocates the ability to provide more useful policy input to both the Governor and Legislature.

We urge the Legislature and the Governor to consider the following priorities:

1. **Increasing Supports and Services for People Who Live at Home and May Require Out-of-Home Placement.** Individuals, who in a former age would have been institutionalized, have remained with aging parental caregivers throughout their adult lives. Now many of these caregivers have lost their ability to adequately care for their adult child with developmental disabilities, due to their own age or disability. In 1998, the New York State CARES program was started to provide out-of-home, community-based care to address the waiting list for service placements. New York State CARES has since been discontinued and the waiting list has increased to crisis proportions.

According to available dataⁱ compiled by David Braddock of the University of Colorado, 64% of people with developmental disabilities in New York State, or 198,592 individuals, live with family caregivers. Of that number 54,309 live with family caregivers – usually parents – who are age 60 or older. Many of the individuals in this cohort who provided loving care for many years are no longer able to provide safe and appropriate care for their loved one. Many more parents will be in the same circumstance in the next few years.

New York State's approved HCBS Waiver includes definitions for Priority I and Priority II individuals in need of service. Priority I includes many people at home at imminent risk of homelessness or inflicting harm on themselves or others. It also includes people (special populations) inappropriately placed in out of state facilities, nursing homes, and hospitals. Priority II individuals live under similar but slightly less desperate circumstances.

Data on Priority I and II categories is not fully available or reliable. Extrapolating from what data is available, NYSARC estimates that there are roughly 6,000 Priority I and II individuals in need of services across the State.

It is not possible to fully discern what the State budget contains to address the needs of these high priority individuals. We applaud the Governor for recommending \$60 million (\$30 million state share) to develop 3,500 opportunities for a variety of individuals in FY 2015-16.

But we are not certain how this money will be spent and, in particular, which group of individuals – people leaving developmental centers, people aging out, people returning from out-of-state placements, people living at home -- will be served from these funds. The budget also shows that an estimated 474 "community beds" will be developed during FY 2015-16, but again we are left to guess who might be able to access these additional residential resources.

The Administration maintains that the lack of specifics is intended to give them the flexibility to allocate resources in line with changing circumstances. We believe that the Legislature, as well as NYSARC's families, should know how these funds will be spent.

- a. ***Recommendation:*** NYSARC strongly supports the Governor's budget request for \$60,000,000 (\$30 million state share) to develop 3,500 new community based residential and day opportunities, but asks that a portion be designated for people at home in need of additional supports. In addition, NYSARC recommends that an additional \$30,000,000

(state share) be dedicated to double this expansion of residential and day opportunities for people living at home in need of additional supports or out of home residential care. NYSARC believes that the Executive's current funding request, while very much appreciated, is far too small to meet the needs of people living at home, especially given the competing demands for those funds among various populations.

- b. **Recommendation:** OPWDD has established a "Front Door" process that people with disabilities must utilize when seeking services. Not all regional offices are fully staffed to effectively complete fundamental tasks such as determining eligibility, performing strength/need assessments, and matching individuals to appropriate services. ***This directly impacts the ability to place individuals with aging parents in needed out-of-home services.*** NYSARC requests a review of OPWDD staffing levels to ensure completion of these functions in a person-centered manner. We also encourage collaboration with providers to address the needs of individuals in immediate need for services.
- c. **Recommendation:** The Legislature should incorporate budget language requiring specific measurable goals for development of a range of opportunities, residential and nonresidential, for people living at home that are in need of other services. Additionally, the Legislature should ask the Governor to give a reasonable estimate of the extent to which those goals are expected to be met upon the release of the FY 16-17 budget.

2. **Employment Transformation** - Transformational goals include maximizing the level of integrated and competitive employment for people with developmental disabilities. Competitive employment is possible for many, but unrealistic for some. According to Disability Statistics, of all noninstitutionalized persons with cognitive disabilities in New York State ages 21-64, only 22% were employed in 2012. ⁱⁱ

This statistic underscores the challenge of finding competitive integrated employment for people with developmental disabilities. This challenge can only be met if sufficient resources are dedicated to critical supports. These include start-up funding (e.g. pre-operational lease, rehabilitation, and acquisition costs) to enable providers to expand the creation of integrated and competitive business opportunities for people for whom employment is otherwise unavailable. To date this has included "Just a Buck" franchises, Dollar Stores, Fresh Markets, and thrift stores. Additionally, rates for Supported Employment and Prevocational Waiver Services must be sufficient to implement the State's transformation goals for employment given the very intensive needs of some individuals.

Transportation is also vital to the success of employment for people with developmental disabilities. You cannot get and keep a job if you cannot get to it on time. It will be necessary to coordinate existing resources across multiple transportation providers in order to maximize efficiency and capacity. Coordination requires special trip routing software which is currently not funded.

- a. **Recommendation:** Add \$5,400,000 (state share) for transportation costs per year for approximately 1,000 people coming out of workshops and 2,000 new individuals obtaining employment. Other costs are already funded per OPWDD's existing plans.
 - b. **Recommendation:** Add \$3,000,000 to make rate adjustments and fund 1,000 additional individuals in Supported Employment (SEMP) for FY 2015-16 in accordance with DOH and OPWDD goals and per the new rate methodology.
3. **Transformational Costs Need to be Adequately Funded** – Transformational goals include moving people with developmental disabilities into less intensive settings, closing Intermediate Care Facilities (ICFs) which provide the most intensive level of care, moving people into smaller settings and continued deinstitutionalization. These systems changes require more, not less, spending as people move to small day and residential settings where more, not less staffing, is required. The budget appears not to recognize many of these costs.

Supportive Individualized Residential Alternatives (IRAs) are especially critical and free up opportunities in 24 hour supervised IRAs for people who are underserved and people who live at home. Enhanced supportive IRAs also facilitate the required transformation of ICFs. Enhanced supportive IRAs are more intensive than typical supported apartments but less intensive and costly than traditional IRAs. This shift toward less restrictive care is consistent with State policy and its ICF transformation goal.

Recommendation: Add \$11,250,000 to fund direct support hours for 750 individuals expected to make the transition to supportive IRAs in FY 15-16. Ultimately this saves \$13,500,000 which would be incurred if these individuals were served in more intensive and costly settings.

4. **The System of Special Education Preschools is Threatened with Extinction Under this Budget**
A recent State Education Department (SED) report to the Legislature concludes that special education preschool programs are funded at approximately 94% of reimbursable costs and even less compared to actual costs. Preschool programs have gone 6 years without tuition increases (called "growth factors") and additionally, are subjected to an SED annual rate reconciliation process that further reduces funding each year. Under these conditions the entire system of preschool special education is unsustainable and it will face collapse if this situation persists. We project that without growth factors and necessary changes in the tuition methodology nine of NYSARC's remaining 19 comprehensive 4410 preschool programs will be forced to close within the next 2 years.

While audits by the State Comptroller have recently focused on certain special education preschool services that may have engaged in fraudulent or wasteful practices, we must not lose sight of the value of the reputable programs that have successfully reduced the long term cost of special education programs.

- a. **Recommendation:** Add a 4.8% growth factor to the preschool funding formula for the 2015-16 school year, beginning on July 1 --the same increase in school aid recommended by the Governor for the 15-16 school year. Valuable preschool services should receive the same increase.
 - b. **Recommendation:** Include an absentee factor to balance reimbursement which is otherwise based on actual attendance to avoid penalizing preschools with the loss of revenue on account of routine absences over which they have no control.
 - c. **Recommendation:** Add \$30,000,000 to fund a 4410 preschool safety net pool for providers in fiscal distress. A safety net pool would prevent the closure of more schools and could be used for essential renovations or one-time cash infusions while schools in crisis wait for a more permanent fix for 4410 preschools rates including a statutory index for a growth factor and various regulatory reforms.
5. **Chapter 853 School Age Special Education** - Chapter 853 schools provide a free and appropriate public education for school age children with the most severe disabilities whose local school district are unable to meet their needs. Unlike public education, non-profit 853 schools went for 4 years with zero increases and received a modest increase for the past 2 years. As a result, these schools are struggling to retain and recruit teachers and continue to pay all of their fixed costs (heat, insurance, rent/mortgage, etc.).
- a. **Recommendation:** Provide a 4.8% growth in annual tuition rates for Chapter 853 schools.
 - b. **Recommendation:** Add \$25,000,000 to fund a Chapter 853 safety net pool for deferred maintenance. Chapter 853 schools lack a tuition rate methodology that provides funding for maintenance and repair. This addition would greatly enhance the fiscal viability of Chapter 853 schools.
6. **Early Intervention** – The Early Intervention program serves infants and toddlers ages 0-3. Many of these children have severe disabilities. Research has shown that comprehensive and coordinated Early Intervention services are a successful means of minimizing the need for lifelong services. Despite the effectiveness of this program in dealing with intensive needs, rates for Early Intervention services have not increased in 20 years. Many providers have thus ceased providing services and others will follow if rates are not enhanced.
- Recommendation:** Add a 4.8% rate increase for Early Intervention services for the 15-16 the school year beginning on July 1. 4.8% is the same increase in school aid recommended by the Governor for the 15-16 school year. Valuable Early Intervention services should receive the same increase.

7. **Nurse Practice** – Article 7 amendments to the Nurse Practice Act (NPA) will apply the current exemption allowing Direct Support Professionals to administer medications under the supervision of a registered nurse in certified settings to noncertified settings. This is critical in order to expand the availability of noncertified settings and will provide people with developmental disabilities the opportunity to choose integrated community based residential and day services.

Recommendation: Support the Governor’s proposed Article VII language extending the NPA exemption to noncertified settings in order to allow for Direct Support Professionals to administer medications in those settings.

8. **Crisis Respite** – There is an urgent need for specialized crisis respite facilities to care for individuals with developmental disabilities experiencing behavioral episodes. Many individuals requiring crisis respite are currently in, or referred to, community hospital psychiatric wards due to the lack of appropriate supports and services.

Recommendation: Add \$4,000,000 to fund voluntary operated START (Systemic, Therapeutic, Assessment, Resources, & Treatment) programs providing crisis intervention.

9. **Room and Board Supplement** – The Department of Health recently adjusted the State’s Supplemental Security Income (SSI) room and board supplement for IRAs so that the supplement is limited to 64 cents for each 1 dollar of cost. This will result in a cut to providers and may undermine the quality of care.

Recommendation: Add \$22,000,000 to bring the room and board supplement up to actual cost.

10. **Funding to Settle the Centers for Medicare and Medicaid Services (CMS) Audit** – In July 2014 CMS issued a final audit report concluding that the New York Medicaid rates for developmental centers were excessive. The State is currently in negotiations to settle this audit.

Recommendation: NYSARC strongly supports the Governor’s efforts to challenge the findings of the CMS audit and seek a permanent resolution. NYSARC supports the Governors’ proposal to set aside appropriate reserves for any final settlement that will avoid the necessity of enacting any further cuts in the OPWDD community-based service system—and thereby ensure that people in need of these services are not penalized for fiscal decisions that they did not make.

11. **The Justice Center for People with Special Needs Must Shorten the Current Period for Completing Investigations** – Although the Justice Center has sought to expedite the conduct of its investigations, many investigations still take more than 6 months to close. These delays exact a significant system wide cost. Employees charged with abuse or neglect must be placed on leave while awaiting the disposition of a case. Meanwhile additional employees must be hired to backfill the vacant positions and ensure that care is not disrupted. Thus, the provider often pays two salaries simultaneously to fill a single position—which we estimate may cost the system as much as \$40,000,000

Recommendation: Add \$41,690,000 to hold providers harmless for extraordinary costs created by investigations not completed within 60 days, as is generally required by statute.

CONCLUSION

We applaud the Governor for fully funding the two year direct support professional COLA enacted last year by the Legislature; the additional \$60 million for development; and the absence of more cuts.

However, a number of significant challenges remain for our families related to the uncertainty of the Transformational Agenda; lingering questions about the future of managed care; and a growing waiting list of people in desperate need of services. Many families feel forgotten and are vocal about their fear of what will happen to their children when they are gone.

We eager to work in partnership with the Legislature and the Governor to make it clear that such desperation is absolutely unnecessary.

Our families are your constituents; your neighbors; your friends; and, for some of you, part of your own family. In certain parts of the state, our Chapters are the largest employers in the region, making a significant contribution to the economic activity of their communities.

Our families very much look forward to working with you on this budget and during the course of the legislative session.

ⁱ David Braddock, et al, The State of the State in Intellectual and Developmental Disabilities: Emerging from the Great Recession, University of Colorado School of Medicine, January 2015 Pre-publication Proof, Stateofthestates.org

ⁱⁱ Erickson, W., Lee, C., von Schrader, S. (2014). Disability Statistics from the 2012 American Community Survey (ACS). Ithaca, NY: Cornell University Employment and Disability Institute (EDI). Retrieved Feb 23, 2015 from www.disabilitystatistics.org